

Madame Chairman and members of the committee, my name is Lisa Haney and I live in Great Falls. I would like to start by thanking each and every one of you who have made Medicaid Waiver and Big Sky Bonanza a reality. I would also like to thank you for allowing me the privilege of speaking before you today. I have two children, Christian and Andrew, who were diagnosed in 2001 with Duchenne Muscular Dystrophy. Christian is 13, in 7<sup>th</sup> grade and Andrew is 11 and in 5<sup>th</sup>. They both attend public school, have friends, get into trouble, fight quite often, race each other in their wheelchairs and besides their disability, are not much different than other kids their ages. For those of you who are not familiar with Duchenne Muscular Dystrophy, it is a progressive muscle wasting disease which weakens all of the muscles of the body, taking away the ability to walk, lift your arms, stand up from bending over and eventually the ability to breathe on your own. My uncle, who also had this disease passed away when he was 27. My mother and I are carriers of Duchenne Muscular Dystrophy. My mother had to go onto disability since it has since weakened her legs and trunk muscles and is trying to get on the waiting list for Medicaid Waiver. >

At the time the boys were diagnosed, my husband and I both worked full time. We knew we needed some assistance but we also knew we had to continue working, doing everything we could do to pay our bills, maintain a good quality of life and take care of our home and family. Fortunately, we were approved for the Medicaid Waiver program. Thanks to that program and the hard work and kindness of the people at Easter Seals, we now have a home that is accessible from the outside, a handicap accessible bathroom, widened doorways and an accessible van that fits both wheelchairs. Before we received these services, we had to park Christians \$13,000 power wheelchair in the garage in the dead of winter. He also had to brush his teeth in a bowl outside of the bathroom door after he broke his arm and lost the ability to walk.

My husband has been able to maintain his job, but as a result of the progressive and worsening nature of Duchenne Muscular Dystrophy, it became extremely difficult for me to continue working. We were able to pay the bills but I do not know how long it would have lasted if Sacajawea School hadn't had a fundraiser for us, raising almost \$10,000! >

Being able to stay at home with the boys created countless opportunities to improve the boy's health and begin to ward off complications. I have been able to make sure they eat as healthy as possible, take supplements, receive physical therapy at home and at the clinic, give them showers, see them off for school and be home when they arrive home, advocate for them in the school system and in the general public, encourage them, get them involved in recreational programs like Eaglemount and be their primary caregiver.

The boy's health has improved greatly since I have been able to leave my job but the money started to run out so I had to try going back to work. We were fortunate enough to be able to have a care attendant come into our home to see the boys off to school and help them when they arrived home, but I left my job after only 3 days. It was very difficult and uncomfortable for us as a family to have a care attendant in our home so frequently. < The day after I left, I received a pamphlet in the mail about a new Medicaid Waiver program called Big Sky Bonanza. The part that jumped out at me was being able to take

care of my boys and get paid for it! <sup>BSB</sup> We have been on the program since October. So far, we have been able to use Big Sky Bonanza to buy the boys supplements, which are much cheaper than prescriptions drugs, take the boys to get massages, which help prevent any further contractures of the muscles and improve circulation, and have the boys clarinet rental payments made. When I took Christian in to see the pediatric pulmonologist, he said that Christian's lung capacity had actually increased from playing the clarinet. A clarinet is much more fulfilling, cheaper and fun to play than having to use a machine later on to help you breath since you lungs can no longer work on their own. Duchenne Muscular Dystrophy also makes the heart weaker and the fish oil supplements Christian and Andrew take may ward off or delay this! We have been able to have a housecleaning service in our home twice a month which gives me more time to spend with the boys, advocate for them, cook, run errands or whatever may need to be done. We can also be reimbursed for mileage when we drive to Spokane for Shriners appointments. Another blessing of Big Sky Bonanza is being able to hire our own care providers, even friends or family members. Think about how much more comfortable we all feel when we are around those we know and love. Big Sky Bonanza also pays for the boys to do activities with Eaglemount, such as sit skiing and bowling. Last, but certainly not least, has been the ability to be paid for caring for the boys. This has given us an opportunity to take better care of the boys, our home and ourselves. It has also greatly improved our quality of life and made it easier to pay our bills. If it wasn't for Big Sky Bonanza, there was a possibility that we would have to sell our home, which already had so much invested into it by ourselves and Medicaid Waiver and move into an accessible apartment! Now it is possible for us to pay off our bills and have a better quality of life! Big Sky Bonanza has empowered all of us! Both Christian and Andrew love going to school and Andrew made it on the B Honor Roll for the first time not even a month after we got onto the program. > They have both been able to look into the future for the first time and see hope and empowerment! As for my husband and I, we feel blessed in many ways. Things that other people may take for granted, such as being able to say "Yes, Andrew, you may buy that book or go on that ski trip or you can go to Fairmont Hot Springs for the Montana Hope Project reunion" or "Yes, Christian, you can have that cool shirt so the girls will look at you more". The biggest and greatest reward of being on Big Sky Bonanza is being able to see hope in Christian and Andrews faces for the first time.

In closing, I ask that you look into your hearts and know how many, children, elderly, and disabled people are being empowered by programs such as Medicaid Waiver and Big Sky Bonanza and how much more cost effective it is. One day in a nursing home costs more than our Housecleaning services for one year and more than massage therapy twice a month for both boys for a whole year! Thank you all so much for your time!